

Talking about Advance Directives

Mary Ann Forciea MD
Jeanette Gallagher, MSW
Division of Geriatric Medicine
UPHS

Topics

- Introducing the concepts
- Myths/barriers
- Conversations
- Applications: How are Advance Directives really used?

Introducing the topic

- You are admitting a new client/patient. As part of gathering health-related information, you want to determine whether or not the client has completed an Advance Directive.
- What words have you found that clients understand when asking this question?

words

- Living will
- Plan for care at the end of your life
- *“If you were diagnosed with a life-limiting illness, what kinds of treatment would you want?”*
- *“How would you like your wishes honored at the end of your life?”*

Words - 2

- Is a living will the only form of an Advance Directive?
- Health care proxy
- Durable power of attorney for health care
- *Who would you trust to speak for you if you cannot speak for yourself?*
- *Have you named someone to make decisions for you if you are unable to do so?*

- With whom have you discussed your feelings?
 - Surrogate
 - Family in general

summary

- Introduce the topic
- One aspect: care for self
- Another aspect/option: surrogate decision maker
- Talk about your feelings **BEFORE** serious illness strikes.

myths

- An Advance Directive means “Don’t Treat”
 - *Some are used to indicate preferences for generally accepted medical care*
- If I name a proxy, I give up control
 - *“springing” into effect when maker incapacitated*
 - *Maker can override or revoke*
- I need a lawyer to do an Advance Directive
 - State forms
 - witnesses

Myths 2

- The doctors don't have to follow my wishes anyway
 - *Cannot treat against wishes*
 - *Reality can be muddy*
- My family will surely do what I would want
 - *Which family members?*
- Advance Directives are for old people.
 - Terry Schiavo, Karen Quinlan, Nancy Cruzan all in 20s

Barriers

- Fear of access to needed care
 - Economics
 - Racism
- Religious concerns
- Unrealistic expectations about death and dying
- Bad experiences with friends
- “Politeness” – deference to authority

Barriers

“I’m not going to do that because...”

- “I might need that care...”; “The doctors won’t care for me”
- “Those are God’s decisions”
- “I’m sure I will die in my sleep in my house”
- “No one would ever put me through all that at my age”
- “The doctors murdered my aunt after she signed that”
- “I wouldn’t want to tell the doctors what to do”

Conversations

Living Wills

- What you want/don't want (in a 'terminal condition')
 - CPR
 - *If you stop breathing or your heart stops beating, do you want machines used to try to bring you back?*
 - Feeding tubes
 - *If you cannot chew and swallow, do you want to be fed through a tube to keep you alive?*
 - Blood products

Content 2

Less often specified elements

- Kidney dialysis
- Invasive diagnostic tests
- Antibiotics
- Surgery

Conversations - 3

- When you want these choices to apply
- Traditional standards:
 - Terminal condition or state of permanent unconsciousness
 - Treatment that serves only to prolong the process of dying
- Problematic
 - Recognition that death is inevitable
 - Predicting timing of death

Terminal condition

- Pa
- “an incurable and irreversible medical condition in an advanced state caused by injury, disease, or physical illness that will, in the opinion of the attending physician, to a reasonable degree of medical certainty result in death, despite the introduction or continuation of medical treatment.”

Conversations 4

- “Five wishes” document
- ABA worksheet(1-5 scale of intensity of wishes)
 - Cannot recognize or interact with friends
 - Cannot think or talk clearly
 - Are in severe pain most of the time
 - Can’t walk but can use a wheelchair

Conversations with family/proxy

- Start with a story of someone else
 - *Remember that horrible time when Aunt Muriel died in the hospital? I would never want a situation like that, so let's talk now....*
- Blame in on the practitioner, the case manager, the lawyer
 - *Dr Forciea asked me about my thoughts and insisted I talk with you about what I want...*

Family conversations 2

- Use a worksheet, letter, video
- Ask a third party to lead group discussion
 - Case manager/sw
 - NP, MD

Selecting a proxy

- Knows what you want
- Can act on your wishes, not his/hers
- Lives close by
- Will be available in the future
- Can handle potential conflict
 - Within the family
 - With the institutions

Who cannot serve as a proxy

- Younger than 18
- Your health care provider
 - Includes the owner or operator of a facility
- An employee of your health care provider

Ideal discussion

Possible sequence

- Name proxy
 - Functional states that make life worthwhile
 - Wishes for interventions
 - Documentation in record
 - Sharing
 - Periodic review
-
- Perkins, annals of int med 2007

Implementation problems

- Inaccessible or unaware of existence
- Poor proxy choice
 - *“I can’t bear to lose him”*
- Unpredictable courses of illness
 - How ‘massive’ is the stroke?
- Risk management responses
 - Threats from non-proxy family members

Future

- Despite flaws, some preparation for hard choices is better than none
- Values or functional status based directives
- We (the primary care team) should ‘warn patients and families that momentous, unforeseeable decisions lie ahead’, and be prepared to provide guidance that will ‘see patients and families through the fearsome experience of dying.’ (Perkins)